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## **HONORS THESIS ABSTRACT THESIS SUBMISSION FORM**

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ABSTRACT (100-200 WORDS):

When one thinks of the neonatal intensive care unit (NICU), technical skills and electronic monitoring are often considered the most important. While this may be appropriate when considering the maternal-infant experience in the NICU from a medical perspective, it is far from the case from the nursing perspective. As nurses, it is our responsibility and duty to care holistically for our patients' being, which includes their mental and emotional strength as well as their physical and medical needs. In the context of mothers and babies, this means doing everything in nurse's power to promote the maternal-infant bond.

While this may seem to be a daunting task, it can best be accomplished through careful consideration of the feelings of mothers who have had infants in the NICU. A literature review of the mother's experience in the NICU can provide useful information. Once their experiences are understood, the next steps can be taken. This encompasses developing relevant and effective nursing interventions and implementing them to facilitate mother-infant bonding. The three major areas of discussion, based on the literature, include: communication with mothers, actions mothers can take, and redesign of the NICU itself- both its setting and policies.

The following paper should serve as a guide to any future or current NICU nurse who wishes to learn and then employ the best evidence-based practice into their daily clinical settings. It can be used as a reference to empower mothers through comprehensive communication which allows mothers to take an active part in their infants' care. Also included is a look at how nurses can advocate for the redesign of the NICU setting to better facilitate both of these processes.

### **From the Mothers' Experiences**

#### **The Maternal Experience**

Perhaps the greatest overarching theme mothers have agreed upon was the existence of four common steps initiated once they had an infant in the NICU: becoming the mother of a child with a disability, negotiating a new kind of mothering, adapting to a life that will never be the same, and the process of acceptance and denial. These steps were developed and taken from the mothers' own experiences. In fact, these women described their experience of parenting of their preterm infants as one of adapting to risk while protecting their own fragility, preserving their families, and hoping to affirm their futures (Aagaard & Hall, 2008).

Aagaard and Hall (2008) conducted a phenomenological study that led to the discovery of how mothers believe they go forth with the development of their maternal identities. The first step was described as the first sight of their baby then continued with holding and touching their infant, upon which they believed they developed maternal feelings as well as the new sense of obligations. The final steps of developing this identity dealt with learning caregiving competencies and sensitivities for a pre-term infant while simultaneously harboring maternal anxieties and conflicts. Also important to note is that while the mothers were developing these maternal identities, they also described a changing mother-baby relationship dynamic. In their experiences, during the first few weeks they would feel ambivalent about their relationships with their babies. This was due mainly to their fear of attachment to the infant as they were flipping between hope and hopelessness pertaining to whether the baby would survive.

### **Maternal Experience in the NICU Environment**

Obeidat, Bond, & Callister (2009) conducted a qualitative study that sought to obtain an idea of mothers' experiences of the NICU through a series of interviews. Mothers of infants admitted to the NICU shared the ideology that their infant will have complications in growth and development, and that they are responsible for giving birth to an unhealthy infant. Another common grouping of feelings felt by these mothers were: high levels of distress, increased anxiety, depression, and trauma symptoms. These experiences are thought to be related to an infant's prematurity and the NICU environment, as well as physical and emotional isolation from their baby. Being in close proximity with mothers who had given birth to full-term healthy babies while their own babies were in the NICU was also a source of frustration for mothers in the mother-baby unit. The most commonly reported mothers' responses to alteration of the parenting role are the inability to protect the infant from pain and provide appropriate pain

management, anxiety, helplessness, loss of control, fear, uncertainty, and worries about the premature infant's outcomes.

Other notable feelings mothers experienced in the NICU were disappointment and insecurity secondary to newborns being kept away from their mothers and left alone after the intense experience of giving birth. The following themes directly related to the NICU setting identified in the Obeidat (2009) qualitative study were feelings of alienation, despair, grief, of “not being a mother”, of being supervised by the staff and needing permission to touch and care for their infant, and lastly feeling distant and detached. Perhaps the biggest takeaway from this study was the idea by the mothers that there needs to be a group or place that new parents are available to share their feelings in; it may actually be helpful to have women share their birth experiences. This would instill in these women the sense that they are not alone.

### **Actions Mothers Can Take**

Aagaard & Hall (2008) found mothers' experiences moved from ambivalence, insecurity, concern for the baby, and a need to participate and control the care toward adjustment and an existential awareness that was not only a concern for the baby but also a relationship with the baby. In this way, the mothers moved from silence to advocacy. Mothers were also more likely to describe a reassuring ownership of the infant as their baby if they had the opportunity to see, touch, hold, provide skin-to-skin contact, supply breast milk, and care for her infant. Lastly, in being able to begin caregiving actions including touching, soothing, and holding and subsequent physical care in the form of feeding, bathing, positioning, and diapering (Aagaard & Hall, 2008).

Another action central to the mothers' success with connecting to their infants is the process of breastfeeding. Cosimano & Sandhurst (2011) looked at strategies for successful

breastfeeding in the NICU. They found that the mechanics of breastfeeding a NICU infant are not that different from breastfeeding a full-term baby, except for the periods of rest the infant may need. Kangaroo care, placing the baby skin-to-skin on the mother's chest, aids in the bonding process and calms the infant for feeding; also swaddling, holding, rocking, and soft sounds can comfort the infant. It is also important to teach the mother typical feeding cues which include: hand-to-mouth movement, sucking on hands, audible sucking sounds, rooting behaviors, mouthing movements, and gentle tongue thrusting. Infant positioning should be any position that keeps the infant close to the mother's body, with the chin and stomach turned in or facing the mother's abdomen, may be used. Such positions include football hold, side-lying hold, reverse cradle hold, or crossover position. At all times the infant's head should be in a natural position without the need to hyperextend or flex to reach the nipple, and the mother should be encouraged to gently support the breast with the "C" hold as far back from the nipple as possible. Mothers should wait until the infant's mouth is wide open before bringing the baby to the breast, as the feel and scent of the mother's skin and milk will entice the baby to open his mouth. Mothers should use their hands to gently support the back of the infant's head because of weak or underdeveloped neck and mouth muscles. This research also revealed that use of a proper nipple shield increases milk transfer in NICU infants, as well as may ease the work of breastfeeding in preterm infants. Lastly, to maintain a quiet alert state, it may be useful for the mother to rub the infant's feet or back, and if the temperature is stable, to remove the hat or blanket. Nursing care should include teaching the mother the importance of paying attention to listen for audible swallowing from the infant as well as the importance of noting the softening of the breast throughout the feeding and monitoring wet diapers as well as frequent weight checks to ensure adequate intake (Cosimano & Sandhurst, 2011).

Kearvell & Grant (2010) conducted a literature review with the purpose of determining how nurses can support mother and infant attachment in the NICU. Kangaroo care was found to enable mothers to have physical contact with their infant, which enhanced mother infant attachment and contributed to early development. Mothers felt that the process was a warm, calming, and comforting bonding experience that provided both the mother and the baby with the opportunity to get to know one another. Mothers also felt an intense feeling of connectedness during kangaroo care, which provided them with a sense that they were nurturing their infant, which in turn enhanced maternal confidence. Another important finding of this study was that the level of reciprocity between mothers who provided kangaroo care to their infants, including those classified as high-risk was significantly higher than those who did not provide kangaroo care. Mothers also described breastfeeding as “not really considered feeding but more a way of being together, where the main purpose was reciprocal pleasure, comfort, and attachment”. Overall, kangaroo care had a positive, multidimensional impact on mother-infant interaction and attachment, infant development and self-regulation as well as the mother’s mood and behavior (Kearvell & Grant, 2011).

Heffernan, Gustafson, Packard, & Toole (2014) designed a study based upon the concept of a Family Advisory Council, which could promote family centered care in the NICU. Among NICU policy changes which will be discussed later, the FAC reached the decision for bedside nurses to be educated to go beyond their routine practice and allow as much participation from mothers as possible. This care they would help mothers participate in included oral hygiene, diaper changes, feedings, assistance with physical and outpatient therapy, collaboration on developing daily schedules for their baby’s routine care, participation with child life activities, and less restrictive infant holding practices.

Johnson (2008) conducted a literature review to gather the best possible strategies for promoting maternal confidence in the NICU, and generated useful interventions for nurses to use to include mothers in their infants' care, adapted to their conditions. Suggested interventions for stable infants in the NICU include teaching the mother strategies to calm her infant; encouraging the mother to participate in care by changing the diaper, positioning the baby, taking the temperature, and holding the infant; and allowing the mother to help establish the plan of care for the infant. Proposed interventions for critically ill infants include encouraging the mothers' presence at the bedside, assisting the mother in personalizing the bedside, and teaching the mothers to softly touch their infant without stroking to promote attachment.

### **Actions Nurses Can Take**

Nurses are integral sources of knowledge and support for the new mother with a baby in the NICU. Aagaard & Hall's (2008) qualitative study was a platform for mothers to share their experiences with nurses. Some experienced a power struggle over the handling and treatment of their infants. Other mothers experienced disaffection, loss of control, intimidation, and even punishment as a result of perceived inhibitive nursing actions. These mothers felt at times that they had to ask permission from the NICU nurses to care for her infant, as if they were borrowing their children, while at the same time feeling as if they were constantly being supervised by the staff. Lastly, if nurses looked or seemed ignorant, distressed, worried-looking, or were too overly dominant, mothers felt uncomfortable in their care. Mothers then described the traits of a nurse they perceived as successful. The traits of a successful nurse were one that was nice and kind, helpful and supporting, smiling, relaxed, knowledgeable, patient, and willing to repeatedly answer questions. This nurse would also help the mother to get to know her child while reassuring her that her baby is doing well.



Aagaard & Hall (2008) also highlighted various barriers to mothers and nurses establishing successful relationships. One of these barriers was staff failure to form an established relationship with the mothers. This made the mothers feel intimidated to ask questions. Another contributing factor was frequent change of staff, as well as the activity of nurses rushing back and forth from one bedside to another. These factors added strain to the cooperation between staff and mothers, threatened the safety of the infant, and were viewed as disregard of the mother. Steps nurses can take to help break these barriers can begin with informal conversations that also include useful information; this helps the mothers learn from the nurses, as opposed to just informing the mothers. Another crucial piece for nurses to consider is that often mothers might know their babies better than nursing staff. The nurse must consider that the mother may voice what she considers to be the probable cause of her baby's discomfort or illness and might be able to identify possible diagnostic and treatment procedures. Recommendations for the nurse while forming the care delivery plan are as follows: to make sure to acknowledge the role of the parent; foster the parent as a competent caregiver; and integrate the roles of expert, coach, and facilitator into existing nursing roles.

Cosimano & Sandhurst (2011) published an article focused on strategies specific to aiding the mother in her breastfeeding attempts. Nurses should reassure mothers that the infant can breathe, as long as his or her nostrils are exposed. The nurse should also reassure the mother that she is doing a good job and educate her about the proper position and infant latching, while informing her that it is normal for premature infants to suck a few times, rest, and then suck some more. If the infant does not resume sucking, the nurse should encourage the mother to stroke the infant's jaw by his or her ear to illicit the sucking reflex. Finally, nurses should

observe the mother's breastfeeding sessions initially in order to offer suggestions or feedback on positioning, latching, sucking patterns, and possible maternal discomfort.

Obeidat, Bond, & Callister (2009) conducted a literature review focused on determining the experience of mothers in the NICU, and revealed more information about just how crucial the nurse-mother relationship really is. Mothers believed positive mother-nurse relationships facilitate sharing on a deeper level and increase their confidence, sense of control, and feelings of connection to their infants. Nurses were viewed as responsible for the facilitation of families with access to their babies, interpretation, and information. They were also seen as a vital source of emotional support and parental education by the mothers. Nurses were viewed as the sole agent in the mothers' experiences of both joy and despair; for example, if nurses appear ignorant, distressed, or worried-looking, these emotions can transfer to the mother and negatively impact her feelings about the NICU experience. The opposite is also true, in that supportive, caring, and optimistic nurses can transfer positive emotions to the mother and influence their NICU experience to be one of joy.

Chatting was again established as a key method for nurses to effectively engage parents in sufficient information exchange. To be successful, however, chatting is dependent on the type of language used by nurses. This body language should express a sense of caring and support and convey an interest in parents. Examples of such body language would be an open stance with eye contact throughout and nodding to show support of what the parents are saying. Chatting between mother and nurse influences mothers' confidence, sense of control, and feeling of connection to their infant. Nurses must consider cultural influences on mothers' experience of having an infant admitted to the NICU as well. Such factors could be differences in amount of privacy the families and mothers are accustomed to (Asian cultures are generally more private

than Caucasian cultures), who makes the decisions in the family (in Muslim cultures, this is the male), and familial support and visiting practices (Mexican and African American cultures include extended family as being part of their immediate family, and thus may want to ensure they also have access to the NICU). A main nursing implication generated from this study is for nurses to view parents as partners in their care, while helping them to establish a supportive and loving relationship with their fragile infant. Another implication important for nurses to take heed of is that they play a vital role in helping mothers through the stressful and challenging experience of the NICU by developing therapeutic relationships with them, providing emotional support for them, providing them with accurate and clear information, involving them in providing care for their infants, and if necessary accessing certified interpreters to enable them to ask questions and get the information they need. Nurses are encouraged to help mothers talk about the challenging and stressful experience of the NICU and to facilitate their having more time and proximity with their infant (Obeidat, Bond, & Callister, 2011).

Johnson (2008) conducted a literature review centered on finding the best ways to promote maternal confidence in the NICU. Various nursing strategies were generated from this study with the idea that family-centered care is based on developing partnerships that support maternal-infant attachment and role development in the NICU. After admission and stabilization, the nurse should contact the mother to reassure her, give her information, and invite her to visit her infant. Nursing care should focus on measures that decrease maternal and infant stress, including clearing any unused equipment from the bedside, individualizing the infant's bed with a welcome card or picture, beginning an information communication board at the bedside, and decreasing as many of the environmental stressors as possible. Whether the mother is inpatient and on a different unit than her baby, or at home away from her baby, the nurse should give the

mother a picture of her new baby shortly after admission to facilitate maternal proximity and promote attachment. Finally, this study found that if the nurse accompanied the mother to the NICU for her first visit, the mother reported the experience to be less stressful.

Kearvell & Grant's (2010) literature review also centered on how nurses can support mother-infant attachment in the NICU. They found that nurses play a crucial role in assisting the attachment process by promoting and encouraging early mother-infant interaction. Nurses do this by encouraging nursing actions and contact such as touching, talking, singing, comforting, changing diapers, feeding, turning their infant, and responding to behavioral cues. The degree of intimacy mothers achieved with their infant is largely dependent on the nature of the social and emotional environment and support created by the nurse. Those who provide support, assistance, privacy, and have a positive and encouraging attitude towards mothers throughout their experience help alleviate maternal anxiety and promote infant intimacy. Nurses who are sensitive and supportive to the needs of new mothers can help guide and strengthen maternal responses to their infants. Mothers also gain satisfaction and confidence from nurses who provide education, guidance, encouragement, and emotional support throughout new experiences in the NICU.

Nurses should seek further experience, support, evidence-based policies and procedures from knowledgeable practitioners and educational offerings that emphasize the value of strategies such as kangaroo care to the mother and infant. The nurse needs to consider financial and social difficulties that mothers may experience as a result of having their infant hospitalized; this may assist mothers to deal with these multiple and competing demands and therefore have time and energy to connect with their infant. It is also important to care about the way in which mothers feel about themselves and be supportive and respectful of the mothers' input. Nurses can ensure they are doing this by engaging with mothers by being good listeners and sharing their

observations with the mother. They can also talk about the infant with the mother by asking open-ended questions which allow the mothers to feel like they are “good” mothers who are involved in their baby’s care (Kearvell & Grant, 2010).

Griffin (2006) led a qualitative study focused on implementing family-centered care in the NICU, which has many important takeaways for the NICU nurse. This care is able to be delivered when nurses and health care professionals alike demonstrate dignity and respect when they honor family perspectives and choices that are influenced by family values, beliefs, and cultural backgrounds, and incorporate them into care planning and delivery. Parents may desire active involvement in daily decision making, including weaning from respiratory support or transfer to an intermediate care unit. Parents need to know that their observations are welcome and needed; nurses can simply ask, “How does his breathing look to you today?” Nurses are also key components in helping support unrestricted family presence in the NICU; to do this, mothers must be welcomed as essential partners in their infants’ care and the concept of them as “visitors” must be eliminated. It was discovered that mothers judge nurses’ competence not only on the skills and tasks they perform, but also on caring behaviors where responsibility for the infant is shared with the family. Communication between the mother and nurse can influence the mother’s self-confidence, sense of control, and feeling of connectedness with her infant. Nurses can empower mothers to build on their intuitive strengths in caring for their infants. Nurses may struggle with the “softer” side of nursing which consists of sharing care with families, offering emotional support, and placing the needs of family above their own. Also difficult and something nurses need to be mindful of is being aware of verbal complaints about staffing and staff conflicts when mothers are continually present, as these complaints can cause mothers to worry

about competence of care and increase the mothers' stress levels. Overall, this study established that parents are an underutilized tool from whom nurses can learn.

Griffin's (2006) study also focused on nursing and health care provider strategies for effective information delivery in the NICU setting. Information should be unbiased, complete, and accurate, as well as shared in a timely manner. Ideally, ongoing information should be provided to mothers by a small group of trusted providers. When communicating information with mothers, it may be best to begin with an assessment of when they were last updated. This helps prevent unnecessary time-wasting by repeating information they already know, and prevents the unintentional omission of information.

### **Redesign of NICU Environment and Policies**

Another way in which maternal and infant attachment can be better facilitated is through the redesign of the NICU itself; both in setting and policy. Aagaard & Hall (2008) found mothers confided that a great source of their distress came from their infants' appearances, as they were connected to wires and surrounded by machines as well as the simultaneous shrieking of many monitor alarms for different babies. The mothers also felt overwhelmed by the busy, crowded, and noisy environment coupled with the technology and expertise of the nurses and the language and culture of the physicians. Another source of anxiety for these mothers was lack of knowledge of what the equipment, wires, and monitors were for, and why they seemed to alarm frequently for "no reason". A potential policy that could be implemented to help ease these anxieties is the process of guided participation. In this method, nurses closely supervise the mother in her care of her baby; it is more than telling the mother what to do, but rather teaching and answering questions.

Voos, Miller, Park, & Olsen (2015) led qualitative research focused on the goal of promoting family-centered care in the NICU through the implementation of a parent-to-parent manager position. This policy change was developed through a Family-Centered Care (FCC) Committee that includes parents, physicians, nurses, respiratory therapists, discharge coordinators, social workers, physical therapists, child life specialists, and pharmacists. This committee meets monthly and has multiple taskforces working on FCC initiatives. Some such initiatives were an open visitation policy, revision of a Parents' Handbook, production of family TV slides on available NICU resources and processes, and the creation of Parent Notebook and Developmental Calendar. The overall purpose of this initiative was to create a parent-to-parent (PTP) manager position to develop and sustain these FCC initiatives. Funding sources for the salary for this new position and program supplies and materials were sourced through the NICU budget and from ongoing donations. Minimal qualifications for this PTP manager position were a bachelor's degree and well-established people skills, with other values qualities were having a former NICU infant or having first-hand knowledge of a NICU experience and previous program development experience (Voos et al, 2015).

The implementation of the proposed PTP manager position developed in the Voss et al (2015) research began through the manager shadowing staff to introduce the manager to the NICU and hospital culture while providing an overall framework for future goal-setting. This shadowing experience also brought a fresh set of eyes from a parental point of view to see various NICU processes, and thus prioritize the goals of the NICU Family Support Program. The PTP manager attends and advocates for families during family rounds, with their goals being less about giving clinical information and more about how this information was disseminated to the parents and then understood by the parents (Voos et al, 2015).

The next component of the FCC Committee is emotional support and parental empowerment. A monthly family activity calendar was created and posted in several areas in the NICU. This calendar contains information on parent education hours, which are opportunities to provide families with information on a topic that is relevant to their baby's NICU stay or transition to home. These classes are typically led by the NICU or hospital staff, FCC volunteers, or the PTP manager. Various implemented topics included the following: welcome to the NICU, Mom's Dinner (a breast-feeding support group), breathe easy (a support group for infants with a tracheostomy), journaling through the NICU, taking baby home, early days in the NICU, baby sign language, and hold me close (skin-to-skin holding). Social activities were also developed, and some of the ones initiated included: hat knitting, scrapbooking, baby name tag-making, cookies and crafts, Valentine's Day card making, Mother's Day brunch, Father's Day pizza night, monthly milestone calendars, and bravery bracelet making. Additional support was also provided for families through the Parents Offering Parents Support (POPS) mentor match program. NICU parents are offered the opportunity to be matched with a trained, graduate NICU parent recruited by the PTP manager to receive support by phone or email (Voos et al, 2015).

The FCC initiative also focused on creating a welcoming environment with supportive policies. Space was designed to be a place of respite for families in need of a break from the stress of the NICU. The *Wall of Hope* photography project, an inspiring display of past NICU babies and families, is also displayed in this area. The March of Dimes national office contributed to another component of this healing environment through donation of materials, equipment, toys, furniture, and books specifically intended for siblings and children of the NICU infant. A NICU reunion was also developed as a supportive policy; this initiative was spearheaded by the PTP manager who coordinated the volunteers and family activities. These



included the following: a sing-along with a music therapist, face tattoos, and an opportunity for parents to sign up to be POPS mentors (Voos et al, 2015).

Focus was also placed on education promoting FCC through staff training on various topics. These topics included: communication, families in crisis, a father's perspective of a NICU event, and a parent panel of 6 graduate NICU families. The PTP manager also collaborated with several neonatologists on quality improvement (QI) projects such as the Family Flu Shot project, Admission-Orientation project, and the Family Hand Hygiene project. The manager was also requested by other hospital departments to provide staff training focused on FCC and the parent's perspective with topics such as: communication, difficult conversations, families in crisis, and caring for the caregiver (Voos et al, 2015).

An evaluation of the proposed FCC committee and PTP manager position generated NICU staff verbalization of acceptance of families being involved in care. However, their actions do not always reflect their words. Staff behaviors, as well as wording of parent handouts, help set the stage for an FCC unit and build family trust. The next determined step is to establish a NICU Concierge volunteer base, which would be specifically recruited and trained to work with families. This volunteer base could assist families through the admission and orientation process, collecting feedback, while frequently checking in with families during their stay to ensure they receive support and access to all available resources. The possible limitation of this study was that data on family stress and satisfaction with the PTP manager-led programs should be taken to prove the program's worth. Also, the findings from this preliminary study may not be generalizable, as there is a limited literature base for the family-centered care initiative (Voos et al, 2015).

Johnson's (2008) study in promoting maternal confidence in the NICU found that current advances in technology that support the survival of premature and critically ill term infants continue to isolate infants from their mothers. Mothers often report feeling intimidated and overwhelmed as they observe critical care equipment in a loud, impersonal environment. They face barriers imposed by the challenging environment of the NICU that shift their focus from their baby and the "normal" attachment process to equipment and technology that supports their child's life. To combat these environmental issues, many prenatal classes are now including information on premature births and critically ill infants, infant needs, and tours of the NICU as a component of the sessions for all new parents. Another policy change that can be implemented to increase maternal confidence is to be sure that the mother is educated on what to expect when she visits the NICU; furthermore, her first visit, being emotionally overwhelming in nature, should be short and meaningful to create an environment to facilitate environment. Another NICU redesign approach is to hang a simple picture board of the nurses and practitioners with their first names near the entrance to the unit, as this helps anxious mothers and families feel welcomed in the NICU environment. This, coupled with an updated information board at the infant's bedside, helps the mother retain information while feeling welcome at the bedside (Johnson, 2008).

Lee, Carter, Stephenson, & Harrison (2014) formed a multidisciplinary family-centered care committee for discussion on improvements in the NICU environment and setting. The first concern parents and mothers brought up was that they wanted the individuals in their support network to be able to spend time with their infant when they could not be at the hospital. Parents also wanted to stay with their infant during shift change instead of having to put them back to bed and wait an hour before returning to the unit to spend time with their infant. Additionally,

some parents wanted to be with their infant during procedures to provide comfort and support. As a result, the aim of this project was to create a family-centered visitor-management program in the NICU. This was done through meetings with the NICU multidisciplinary family-centered care team as well as key leaders in the NICU and the institution. These meetings were formed to devise a plan supportive of family presence and to gather and support funding. Changes in visitation policy were in fact developed, and consisted of the following: parents were given picture badge ID access to their infants 24 hours a day, and they were able to officially choose family members and friends (a support network) who could come unaccompanied to spend time with and care for the hospitalized infant. These individuals were also given ID badges.

Lee et al (2014) also found that although progress has been made in expanding visiting hours and encouraging parent presence, many NICUs continue to close during nursing shift changes and reports, medical rounds, new admissions, emergencies, and neonatal deaths. In current NICU settings, parents are allowed access 24/7, as well as being allowed the choice to not allow anyone to visit their infant or receive information. Parents and their chosen support network will be asked to provide a picture ID which will be used to create a NICU ID badge. Siblings, on the other hand, must be at least two years old to visit the NICU, and visits are limited to 10-15 minutes at a time. Those who are younger than 14 years old must be supervised at all times by an adult. Sibling presence is limited during cold and flu season and also based on unit activity and the attention/behavior of the child. Other policies in place in current NICU settings allow chosen family and friends to receive general information about the infant's condition during medical team rounds, as well as sharing in the care of the infant as the infant's condition permits (such as holding and feeding) per parent preference. A family services assistant is available seven days a week from 8 am to 10 pm for the family, and as space permits,

two sleeping spaces are available to parents and guardians and grandparents. As far as family and friends who are not part of the “chosen support network” are concerned, they may come with parents from 9 am to 9 pm seven days a week, and due to space limitations only two people are allowed at the bedside at a time unless the infant is in a private room (then there can be four at a time). Children under 14 years old are not permitted unless they are siblings, and everyone who visits the NICU must wash their hands at the scrub sinks at the entry to the nursery.

Various other policies are currently in place in the NICU setting to facilitate a healing environment. Cell phones are allowed in the NICU with ringer on vibrate or silent; however, the use of cell phones for conversations are to take place outside of the NICU or in the waiting area to help provide a quiet environment for all infants. Family members are invited to bring socks or booties, clothes, drawings from siblings, family pictures, and up to two Mylar balloons. Parents are welcomed to call the NICU toll-free number to receive updates and information on their infant; they will be given a PIN number for security purposes (Lee et al, 2014).

The open visitation policies used in these NICUs may contribute to maternal stress and a feeling of obligation on the part of mothers to be at the bedsides of their infants as much as possible. For this reason, limits should be placed on visitation to help facilitate new mothers’ recovery and self-care behaviors. However, adding restricted visitation can add more maternal stress and anxiety while creating an imposed separation between the parents, family, and their sick infant. Post-intervention, parents rated their feelings of being welcomed in the NICU more highly, as well as their experience of the NICU as a caring place. Parents also believed they received all the information they needed about their infant from hospital staff, were able to read and understand teaching materials, felt supported in breastfeeding, knew their assigned nurse every day, and stated that hospital staff introduced themselves by name each day. These positive

responses may be due in part to the new 24-hour parent access to their infants and more face-to-face interactions with NICU staff members (Lee et al, 2014).

A limitation of the study by Lee et al (2014) is that they were unable to determine how sick the infants were at the time the parent survey was completed. Another possible shortcoming of the study was that there was no specific attention paid to the location of the infant's bed or whether it was in an open pod vs. private room; this may have also made a difference in survey responses. Future studies may also include a look at length of stay, acuity, and location of the infant in the NICU because these correlate with parents' perceptions of family-centered care practices.

Kearvell & Grant (2010) identified environmental barriers to kangaroo care in the NICU setting through their literature review. These barriers were infant safety, nursing staff reluctance, nurses' fear of something going wrong, minimal staffing, and time constraints. Evidence-based guidelines are essential, as lack of protocols will inhibit the provision of KC in both general wards and the NICU. To minimize these perceived barriers, these appropriate evidence-based standards must be addressed with consideration to staffing for KC in order to assist in a successful KC experience and facilitate mother-infant attachment. Lastly, patient-nursing ratios need to be considered to accommodate mothers' psychosocial needs as many mothers require more support than what they receive.

Heffernan, Gustafson, Packard, and Toole (2014) proposed another redesign of the NICU setting and policies, manifested as a Family Advisory Council (FAC) tasked with promoting the concept of family-centered care. Senior NICU leaders conducted biweekly open-forum style meetings in which committee members asked for feedback on general issues and topics from FAC parent members. The information gathered from these meetings then go on to improve the

next family's NICU stay. Guest speakers were also included and consisted of pediatric surgeons, financial counselors, and hospital administrators. A policy change developed from the FAC was that only parents would be allowed to call for updates and receive medical information at the bedside.

FAC feedback also established novel communication tools in the NICU including a redesigned NICU welcome packet and an "All About Me" worksheet that parents complete. Also important to this proposed NICU setting is a designated NICU social worker who provides emotional support and identifies concrete resources for families while their child is hospitalized. He or she would also serve as a gatekeeper through which additional support services are established. Another useful resource to this new NICU environment would be child life specialists, who work with patients on developmental care needs, establishing routines, and developing structured play time. In response to feedback, changes were also made to the NICU's established family support system, with concepts such as a parent coffee hour, a parent-to-parent support program, parent relaxation opportunities such as massage, and scrapbooking opportunities. The FAC also initiated the early involvement of an already in place Pediatric Advanced Care Team to meet the needs of families struggling with children with advancing illness. Overall, the FAC provides an unparalleled opportunity for NICU leaders to collect family satisfaction data, assess parental understanding, and to determine parental readiness to care for medically complex infants who are to be discharged home (Heffernan et al, 2014).

Griffin (2006) also examined family-centered care in the NICU, with the main policy-change being a prioritization of family collaboration with the health care team. Collaboration was to take place with healthcare practitioners and administrators in participation in policy and program development, facility design, and professional education. What was found was that FCC

must begin with a vision or philosophy of care statement, and as new staff members are hired their understanding and commitment to FCC can be considered. NICU design should include single rooms, which offer parents a more comfortable place to stay with their baby during the acute stage of illness as well as ample opportunity for rooming-in prior to discharge. In a traditional NICU setting, where separate rooms may not be possible, screens can be used to limit the family's exposure to a new admission or to emergency procedures. Health Insurance Portability and Accountability Act (HIPAA) regulations are not intended to interfere with FCC principles; as such, while staff are mostly aware of who is present in the NICU during rounds, confidential information is shared outside rounds. Also, following an FCC model, parents should be able, if desired, to stay and comfort their infant during invasive procedures and during resuscitation. As such, another potential policy should be patient education on nonmedical skills that can help decrease a baby's discomfort and pain, such as pacifiers, administration of sucrose, positioning, and swaddling.

### **Conclusion**

As nurses, it is our duty to advocate for our patients to be sure that their needs are met in a self-sufficient manner. This becomes especially important in settings such as the NICU, where our "patient" is actually the infant and the parents, each with their own set of unique needs. However, through careful communication with the mother while respecting her input and feelings at all times, we can begin to build a relationship with her that will enable her to gain the confidence necessary to care for her NICU infant. With this confidence, the mother can participate in activities that not only facilitate bonding between she and her infant, but also are important care tasks vital for the baby's ability to survive and thrive. Through allowing mothers the greatest amount of hands-on experience possible, we are providing them the opportunity to

participate in “normal” mothering tasks which allow them to relieve stress they may feel related to their inability to be completely hands-on with their critical infants. In order to see that the changes proposed actually occur, we need to advocate for the redesign in NICU policies and settings, as well as educate ourselves and others on the importance of empowering mothers and the strategies that work best to accomplish these goals.



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